

'It's not one size fits all': a qualitative study of patients' and healthcare professionals' views of self-management for bronchiectasis

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ABSTRACT

Background Bronchiectasis is a chronic respiratory condition that impacts significantly on individuals and healthcare services. Self-management is recommended in clinical guidelines for bronchiectasis as an intervention to enable patients to manage their condition, yet there is little evidence to support it.

Methods Three face to face focus groups (17 adults with bronchiectasis) were conducted at three National Health Service (NHS) sites in North West England. Additionally, semi-structured telephone interviews were undertaken with 11 healthcare professionals (HCPs), including doctors, nurses and physiotherapists. Thematic analysis identified common themes and occurrences verified by independent audit.

Findings Four common overarching themes were identified: *the meaning of self-management; benefits; barriers and influencers to self-management*; subthemes varied. Both groups recognised component interventions. Patients highlighted that self-management enabled them to learn what works and moderate behaviour. Aspects of delivery and structure were important to HCPs but a 'make do' culture was evident. Benefits for both groups included empowering patients. Common barriers for patients were time, mood and lack of access to support which could mitigate engagement with self-management. HCPs identified barriers including patient characteristics and lack of resources. Influencers for patients were peer, carer and psychosocial support, for HCPs influencers were individual patient attributes, including ability and motivation, and HCP characteristics such as knowledge and understanding about bronchiectasis.

Summary This is the first study to explore patients' and HCPs' views of self-management for bronchiectasis. The need for an individual, flexible and responsive self-management programme specific to bronchiectasis was evident. Personal characteristics of patients and HCPs could affect the uptake and engagement with self-management and HCPs knowledge of the disease is a recognised precursor to effective self-management. The study identified key aspects for consideration during development, delivery and sustainability of self-management programmes and findings suggest that patients' psychosocial and socioeconomic circumstances may affect adoption and activation of self-management behaviours.

BACKGROUND

Bronchiectasis is a long-term respiratory condition with a significant impact on quality

Key messages

What is the key question?

- ▶ What are the views, preferences and experiences of patients and healthcare professionals (HCPs) regarding self-management for bronchiectasis?

What is the bottom line?

- ▶ An individualised, flexible and responsive self-management programme is needed for patients with bronchiectasis, provided by HCPs knowledgeable about the disease and management.

Why read on?

- ▶ This qualitative study has revealed key considerations that will inform development and delivery of future self-management programmes for patients with bronchiectasis. Future research is needed to explore further the influence of psychosocial determinants of patients' engagement with self-management interventions.

of life, morbidity, mortality and use of healthcare resources.^{1–3} The disease manifests as chronic airway inflammation, impaired mucociliary clearance and structural lung damage leading to recurrent infections, persistent cough, sputum production and exacerbations. Diagnosis is often clinically defined and confirmed by high-resolution CT (HRCT).⁴

The prevalence of bronchiectasis appears to be increasing, though true prevalence may be influenced by other factors such as improved diagnosis using HRCT and inaccurate diagnosis due to comorbidities.^{5–9}

The aim of therapeutic management is to break the recurrent cycle of inflammation and infection, to preserve lung function, reduce exacerbations and complications, and improve health-related quality-of-life.^{10 11} Antibiotics are the frontline therapy for bronchiectasis and most international guidelines also recommend airway clearance techniques (ACT) and pulmonary rehabilitation (PR).^{11–12}



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Self-management has been defined as actions taken by individuals and others to mitigate the effects of a long-term condition and maintain a good quality-of-life.¹³ Self-management strategies have improved quality-of-life and reduced service burden in other chronic respiratory conditions such as chronic obstructive pulmonary disease (COPD) and asthma,^{14 15} with potential to achieve similar benefits in bronchiectasis. Adherence to prescribed treatment may be poor¹⁶ and it is therefore vital that patients are supported to manage their condition more effectively.

International guidelines for bronchiectasis include recommendations for self-directed activities such as exercise and ACT,^{1 10–12} but the majority do not specifically refer to self-management or patient education. However, the most recent British Thoracic Society guidelines explicitly recommend that ‘people with bronchiectasis have an individualised written self-management plan’ as the first element of a five-step plan.¹⁰

A Cochrane systematic review of self-management interventions found insufficient evidence to assess the benefits for patients with bronchiectasis¹⁷ and added to the call for research to define and develop these interventions.^{9 10 18} The aim of this study was to explore views of self-management with key stakeholders to inform the design and development of future self-management programmes.

METHODS

Design

This was an inductive exploratory qualitative study including patient focus groups and one to one interviews with HCPs. These complementary approaches reinforced validity through methodological and participant triangulation. Triangulation refers to comparison and meshing of different data to enhance credibility and add depth to findings.¹⁹

Patient and public involvement

A project steering group was convened and consulted on key project decisions, this included members of the multidisciplinary team with an interest in bronchiectasis and three patient representatives of different ages, employment status and levels of morbidity. These patient representatives guided and commented on study materials and the interview schedules.

Participant recruitment

Patients and HCPs were recruited on a voluntary basis by three independent institutional gatekeepers (clinicians) based in three National Health Service (NHS Trusts in the North West of England. Inclusion criteria for patients were: >18 years; diagnosis of bronchiectasis confirmed by HRCT; English speaking. Patients were excluded if: they had a diagnosis of bronchiectasis secondary to cystic fibrosis; or had an acute exacerbation at the point of recruitment. Inclusion criteria for HCPs were: >18 and

involved in the care of patients with a diagnosis of bronchiectasis. All participants were provided with an information sheet explaining the study and given an opportunity to ask questions prior to and after providing informed consent.

Data collection

Interview and focus group schedules were developed based on factors related to self-management harvested from previous systematic reviews,^{17 20} and published guidelines,^{10 11} including a search of grey literature. This was supported by a call through professional organisations for relevant local policies. The draft interview schedules were discussed and finalised with the project steering group which included PPI.

Three focus groups were conducted with adult patients by two researchers (DL, AT) from May to October 2019. Semi-structured telephone interviews with HCPs caring for adult bronchiectasis patients were conducted by AT between February and April 2019. All data were digitally recorded and transcribed verbatim (AT).

Data analysis

We used a thematic approach to data analysis²¹; this requires the researcher to familiarise themselves with the data in order that common themes, occurrences and outliers are identified to provide some level of understanding, explanation and interpretation. While the findings may not be generalisable it may be possible to draw tentative conclusions that may be applicable to a wider population. A number of procedures were adopted to safeguard and maintain authenticity and credibility, these included independent audit by a second member of the research team and the use of verbatim quotes. Individual interviews were primarily analysed by CK and focus groups by DL.

FINDINGS

A total of 17 participants took part in three focus groups. Eleven HCP interviews were conducted at three different NHS sites in the North West of England. All focus groups lasted for between 60 and 90 min and interviews lasted 30 min on average. Sociodemographic details of patients were recorded to enable transcripts to be analysed in context (table 1). The demographic data of HCPs (table 2) were recorded to establish clinical experience of individuals and context of their clinical practice as related to self-management of patients with bronchiectasis.

For patients and HCPs we identified four common overarching themes: *the meaning of self-management; benefits; barriers and influencers to self-management* and subthemes that differed between the two groups (table 3). The themes are discussed later supported by verbatim quotes: patients and HCPs are identified with a number, for

Table 1 Participant characteristics of focus groups

| | |
|-------------------|--|
| Gender | Male (n=5), female (n=12) |
| Age (years) | Mean (72.94), median (71), range (62–88) |
| Employment status | Retired (n=16), self-employed (n=1) |
| Area | Rural (n=5), urban (=12) |
| Comorbidities | Multiple (n=7; range 2–7), one (n=8), none (n=2) |
| Marital status | Married (n=10), single/living alone (n=7) |

example, P7, followed by the line number in the transcript, for example, HCP4:46.

Meaning of self-management: patients

Patients and HCPs discussed their definition and interpretation of self-management. For patients, this theme comprised identification of *components of self-management*, *learning what works* and *moderating behaviour*. *Components* included chest clearance and breathing control, medication and rescue packs, education (of self and carers), diet and exercise. *Learning what works* for them was deemed important, giving a sense of autonomy and control:

‘... you can reduce it [medication] and you’re okay’
 ... So, I’ve reduced it ... it’s a good side to control,

to be able to do it yourself, but you have to be very careful, don’t just stop it. (P3:507)

Making autonomous decisions under the direction of a clinician was recognised as a significant part of self-management and patients were aware of the importance of compliance and *moderating behaviour*. This was discussed openly:

If you’re not prepared to do exercises and do everything you’re supposed to, like take your medicine, then it’s not going to work. (P15:32)

Patients overall felt positive about self-management, some related it to specific models of delivery, for instance PR, but most recognised it as a way of enabling them to control their condition.

Meaning of self-management: HCPs

HCPs similarly offered insight regarding *components* of interventions that included patient education sessions (disease and course of disease, smoking cessation, diet, influenza vaccinations, avoiding infection, travel, etc), information for patients regarding who and when to contact for advice, chest clearance exercises and devices, coping strategies, and benefits of general exercise. Recognising signs of infection early was stressed, with prompt action and follow-up recommended.

Table 2 Demographics of healthcare professionals

| Participant | Clinical role | Length of service in clinical role | Specialist area of practice | Type of service area | Approx. number of bronchiectasis patients seen in an average month |
|-------------|--------------------------------|------------------------------------|---------------------------------------|----------------------------|--|
| HCP1 | Physiotherapist | 8 years | Respiratory (COPD and bronchiectasis) | Primary care—community | 10–15 |
| HCP2 | Physiotherapist | 24 years | Medicine and respiratory care | Secondary care | 13 |
| HCP3 | Physiotherapist | 12 years | Respiratory/self-management | Primary care—community | 10–20 |
| HCP4 | GP | 18 months | Chronic respiratory diseases | Primary care | 30 |
| HCP5 | Physiotherapist | 17 years | Respiratory | Primary care | 10 |
| HCP6 | Respiratory medical consultant | 6 years | Cystic fibrosis and bronchiectasis | Secondary care | 60 |
| HCP7 | Respiratory nurse | 13 years | Respiratory | Integrated care | 50 |
| HCP8 | Respiratory nurse | 6 years | Respiratory | Primary care | 10 |
| HCP9 | Respiratory nurse | 7 years | COPD and bronchiectasis | Primary and secondary care | 10–20 |
| HCP10 | Respiratory registrar | 2 years | Occupational respiratory disease | Secondary care | 8–10 |
| HCP11 | Physiotherapist | 29 years | Respiratory | Primary and secondary care | 6–10 |

COPD, chronic obstructive pulmonary disease; HCP, healthcare professional.

**Table 3** Overarching themes and subthemes

| Meaning of self-management | | | | | |
|----------------------------------|-----------------------------|-----------------------|--------------------------------|-------------------------|-----------------------|
| Patients | | | HCPs | | |
| Components | Learning what works for you | Moderating behaviour | Components | Delivery and structure | |
| Benefits of self-management | | | | | |
| Patients | | | HCPs | | |
| Manage and prevent exacerbations | Proxy for HCPs | Control anxiety | Empowering patients | Clinical outcomes | Psychosocial benefits |
| Barriers to self-management | | | | | |
| Patients | | | HCPs | | |
| Time-consuming | Lack of access to HCPs | Mood | Characteristics of the patient | Lack of tools/resources | resentment |
| Influencers on self-management | | | | | |
| Patients | | | HCPs | | |
| Peer, carer and social support | Knowledge of HCPs | Psychological support | Characteristics of the patient | The HCP | |

HCP, healthcare professional.

Discussion of *delivery and structure* in relation to interventions was prominent in all HCPs' responses with many advocating PR as a format for introducing self-management. Integration as part of the clinical pathway was also recognised, with emphasis, but not consensus, regarding optimal delivery of education sessions:

One to one because I think some of the quieter patients who have less understanding will feel more confident to ask questions, but in a group I think people will also hear the way someone else might manage their condition or might recommend something they have not thought of. (HCP7:169)

Others spoke of whether an education session should be for individuals with single disease or whether mixed disease cohorts were feasible, again no consensus was apparent, but availability of resources governed this to some extent.

All participants were asked about their thoughts on technology for guiding self-management; responses varied with some HCPs favouring digital technologies while the benefits were unclear to others:

The number of apps in asthma have shown never to work, so ... why would it work in bronchiectasis? (HCP6:110)

Patients' motivation, employment status, age and whether 'technology savvy' (HCP3:158) were factors cited for engagement with technology. Overall, there was no consensus regarding benefits of technologies to support self-management interventions.

Benefits of self-management: patients

Exacerbations were considered important to patients because of the impact on lifestyles and coping

mechanisms. The self-management plan was referred to as a way of enabling patients to *manage and prevent exacerbations*. This enabled one individual to avoid taking antibiotics that were associated with uncomfortable side effects:

... I couldn't get rid of the infection. So, they kept giving me antibiotics, which were making me not well and making my skin all blotchy and whatever. And I see [doctor's name] ... he gave me a self-management plan and that was in March and I've done it ever since ... And I haven't had any antibiotics at all. (P14:11)

Some described benefits of self-management as a *proxy for HCPs* when there was no access. Patients also used self-management techniques to *control anxiety* about their condition.

Benefits of self-management: HCPs

HCPs regarded self-management as a method of *empowering patients*, enhancing their self-care abilities:

I think it puts the patient right at the centre of care. (HCP3:115)

HCPs considered self-management as conferring control and ownership for patients, reinforcing self-confidence. *Clinical outcomes* were directly related to self-management with earlier identification and intervention resulting in fewer exacerbations with quality-of-life benefits for patients. *Psychosocial benefits* were also recognised, particularly increased confidence and independence:

At the end (of the exercise programme), they'll be better, and it makes a difference to their everyday life. (HCP1:83)

HCP's also noted the benefits of peer support for increasing self-confidence, sometimes through attending PR or group education sessions.

Barriers to self-management: patients

Patients discussed the challenges of balancing *time-consuming* treatment against personal commitments, such as caring responsibilities that may lead to negative impacts on self-management:

I sometimes have to shorten one of my inhaling things because I haven't got the time. (P15:121–122)

Lack of access to HCPs with appropriate specialist training and access to reliable information on bronchiectasis also featured in discussions:

I went to my GP and tried to speak to a physio and a respiratory nurse. They both said, I don't know anything about it [bronchiectasis] and that I'll have to speak to my specialist. Actually, trying to get information to how to manage it was really, really difficult. (P17:238–241)

Long waiting lists, lack of continuity and consistency of care were also seen as barriers:

... it's just amazing, you never see the same person twice. (P13:214)

Patients talked about their *mood* as influencing their ability to engage in self-management featuring lethargy, fatigue and depression:

It's the pure tiredness. You're really exhausted, and you think, 'I've got to set the machine up and I can't be bothered'.' (P6:A607)

Feeling down when quality-of-life is perceived to be poor was also linked to a lack of motivation for self-management:

I think when you've had infection, after infection, after infection you just go so low ... you know, why me, what have I done to deserve this and all that type of stuff. I start to feel very sorry for myself. (P10:301)

Barriers to self-management: HCPs

HCPs also felt that *characteristics of patients*, for instance low levels of resilience, impacted on patients' motivation and ability to self-manage:

Sometimes patients just don't have the same coping strategies to deal with tasks that they need to do for self-management. (HCP11:136)

Physical symptoms were also deemed to impact; cough was a significant issue that affected patients' abilities to attend group gatherings and therefore engage in self-management:

A lot of people don't like coughing ... You have to expect people to expectorate and certainly for women there's a social stigma towards coughing sputum. (HCP9:124)

Coughing was linked to fatigue and social isolation which was felt to impact further on patients' motivation and abilities: a combination of barriers preventing effective engagement in self-care: 'It's hard work for them' (HCP2: 66).

... if somebody is socially isolated, hasn't gone out, fatigued, struggling with symptom burden, their mood's low, their self-worth comes down, they think of themselves as disgusting and somebody who nobody wants to be around. It all just has this negative spiralling effect. (HCP3: 272)

Finally, *lack of tools* and/or *resources* was regarded as a significant barrier to HCPs promoting and supporting self-management. Some admitted that as services were 'geared towards COPD' they often had to make do with available resources:

We'll give them [patients with bronchiectasis] the same leaflets, but we just explain to them that you haven't got COPD you've got bronchiectasis, but it's similar signs and symptoms of a chest infection and what to do next. (HCP8:205)

In relation to efficient delivery of self-management interventions, participants voiced frustration with clinic waiting lists, understaffing, and lack of patient information.

Influencers on self-management: patients

Relatedly to HCPs highlighting the benefits of peer support, patients also valued *peer, carer and social support* and format of groups (citing the focus group in this extract) was deemed to be helpful:

... I think focus groups like this enables people with the same problems get together and bouncing off each other. (P12:106)

In some cases, family members themselves delivered interventions such as chest physiotherapy. In this context participants acknowledged the need to educate the family and carers in addition to themselves. For those who lived alone, reliance on friends and neighbours was important, sometimes just needing somebody to 'bounce off' (P7:319).

Knowledge of HCPs was viewed as fundamental to patients' engagement with self-management. Physiotherapists were recognised as central to care and patients were aware of the significance of specialist clinicians in contrast to generalists:

They have asthma nurses in GP surgeries. But when it comes to bronchiectasis ... I don't think people are educated at all. (P6:363–364)

Overall, accessibility of help and support and responsiveness of HCPs enabled patients to feel confident with their regimes.

In addition to a need for symptom support, patients recognised the need for *psychological support*, citing engagement in activities such as mindfulness, meditation and yoga. Patients were aware of and discussed occurrence and repercussions of anxiety.

Influencers on self-management: HCPs

In addition to being a barrier to self-management, *characteristics of patients* were also seen as an influencer if strategies could be tailored to individual needs:

Everyone is different. Everyone's symptoms are different. Everyone experiences a condition in a different way. (HCP9:167)

It's not one size fits all (HCP2:106)

Patients' motivation was discussed in terms of priorities and passivity. Participants referred to patients' desire for information and a willingness to learn, attributes driven by personal priorities:

If it doesn't feel important, then they can't find their own reason to do it, then they probably don't do it. (HCP3:104)

Ability to self-manage was perceived by HCPs to be central to engagement with and optimisation of interventions. This subtheme comprised several aspects including patients' literacy and comprehension skills, presence of comorbidities, their ability and willingness to accept responsibility, and resilience. Regarding autonomy, HCPs related this to levels of confidence and their level of activation, sometimes measured using Patient Activation Measures:

... tells us how engaged and activated and knowledgeable for someone to manage their condition ... (HCP5:81)

The relevance of demographics to self-management was at times contradictory:

So younger people are more engaged with self-management (HCP10:32)

I don't think age comes into it. We've got fantastic patients who are in their 80s and 90s; they're very sharp, they know their condition, they're more than capable to self-manage. (HCP8:230)

Although patient characteristics featured in HCPs responses, it was also evident that *HCPs* influence patients' engagement with self-management. Like patients, the importance of knowledge, skills and education were highlighted, particularly in relation to a lack of awareness regarding the disease and management:

... among healthcare professionals, bronchiectasis isn't well recognised or understood. It's often

managed like another lung disease or a serious chest infection. (HCP3:203)

A few HCPs attributed improvements in care to key individuals in the multiprofessional team who champion bronchiectasis, in contrast lack of generalists' knowledge of the condition was highlighted as a potential issue:

How knowledgeable is their GP or nurse on bronchiectasis to be able to explain it to them? (HCP10:229)

Importance of guidelines was recognised as a key driver for the use of action plans. Coworking and partnership were recognised as important for a few, acknowledging the relevance of patients' and HCPs' shared responsibility in the processes of self-management.

DISCUSSION

We explored patients' and clinicians' views of the self-management of bronchiectasis. Our findings highlighted components of self-management programmes and aspects of delivery considered to be important. Moreover, potential barriers to effective implementation were identified.

Structure, delivery and resources

We did not identify formal, structured self-management programmes, but we did find that current guideline recommended evidence-based single interventions, such as exercise and ACT, are often incorporated into daily patient routines. Regular exercise as part of formal PR programmes is recommended for patients with bronchiectasis,^{10 11} and has been shown to improve health outcomes^{22 23}; endorsed further by association between sedentary behaviour and increased risk of hospitalisation.²⁴ ACT was also promoted as an intervention but was recognised as time consuming for patients. ACT is often underused and associated with poor compliance, with the biggest take-up by those with the most severe disease.²⁵ It remains unclear whether a more structured approach to self-management would benefit adherence to such interventions, but motivation of the patient to engage with treatment regimens is clearly important.

Action or self-management plans were used by patients and HCPs to guide management of symptoms, interventions and exacerbations. Self-management interventions that include an action plan have been found to improve quality-of-life and reduce hospital admissions in COPD,¹⁴ although evidence of efficacy in asthma is lacking.²⁶ In bronchiectasis research is scarce; a randomised control trial evaluating a Bronchiectasis Empowerment Tool containing an action plan reported no positive outcomes.²⁷ However, the intervention was burdensome (48 pages long) leading to 50% loss of participants who were reluctant to engage either because it was arduous, or they had developed their own self-management techniques.²⁷ There is clearly a need for self-management

tools that are acceptable to patients and do not add to disease burden; timing of the introduction to the intervention in relation to the point of diagnosis may also be important.

No consensus, from either patients or HCPs, was found to support or refute the use of technology to facilitate self-management. Feasibility and high demand for online access to a web-based bronchiectasis information resource has been demonstrated, but this is yet to be proven in a full clinical trial.²⁸ The UK Government's digital inclusion strategy identified key barriers including age and social deprivation, that should be considered in design of self-management programmes.²⁹

Availability of resources was a key factor with a scarcity of high-quality information and evidence of a 'make do' culture. Lack of materials have been previously identified as an obstacle to effective self-management.³⁰ Lack of availability of specific resources may be perpetuated by a lack of knowledge and understanding of bronchiectasis among generalist HCPs, as highlighted in our study. Specialist education in respiratory care has been found to increase knowledge and impact positively on practice.^{31,32}

Views regarding duration of programmes, review and follow-up varied. For some, contrast between a clinical setting and the patient's own home was considered important alongside the ability to design interventions to suit local needs.

Individual approach

One size does not fit all, and it was clear that a tailored, personalised approach to self-management was preferred by both groups. This notion aligns to the approach of *treatable traits* and precision medicine, which may provide better outcomes for patients with bronchiectasis through a more personalised and precise management plan.³³ Self-management needs to be tailored to individual patients and their condition, as recognised in the PRISMS taxonomy of activities supporting self-management in long-term conditions.³⁴

Peer support was aligned to patients' adherence, motivation and general outlook, with advantages in terms of psychological well-being. The merits of peer support have been highlighted previously³⁵ but not always prioritised by HCPs who often favour symptom management and clinical outcomes.³⁶ Peer support has been found to sustain change in health behaviours³⁷ and patients' engagement with self-management.³⁰ Consensus from our study demonstrates that patients benefit from peer support, but it is unclear whether one-to-one self-management programmes or a group format are most beneficial.

The ability and desire for patients to engage with self-management was a significant factor for HCPs and the use of tools to gauge patient activation was reported. Patient activation is described as knowledge, confidence and ability to self-manage chronic illness and can be assessed by using the Patient Activation Measure.³⁸ It has been

suggested that HCPs educated and trained in supporting behaviour change, as well as the specific condition, have more success with patient activation.³⁹ This could be an important and useful consideration for future bronchiectasis self-management intervention programmes.

Both groups recognised the impact of mood on engagement with self-management activity especially if depression was manifest. Self-management can motivate individuals and reduce anxiety by providing patients with a sense of control, a lack of which can impact negatively on a patient's quality-of-life.² This can influence motivation and adherence and is likely intrinsically linked to availability of social support networks and mitigation of factors associated with poor adherence.^{16,40} A recent review has developed a programme theory postulating that increasing awareness of psychological and social factors may trigger short-term improvements in self-efficacy and quality-of-life in a well-informed population of bronchiectasis patients.²⁰

Other sociodemographic factors, such as family support and finances, may also be relevant to a patient's ability to engage with self-management. There is a recognised social gradient in the health and care of people with bronchiectasis showing that those from deprived communities have worse outcomes.^{8,41} It is not clear whether this is related to better access to healthcare or confounding factors such as smoking and higher incidence of comorbidity in deprived areas.⁸ More affluent groups may self-manage more effectively and have greater access to specialist services, which may impact on survival.⁴² Influence of factors such as literacy, health beliefs and economic factors are less well understood and require further study.

Differences in perceptions from patient focus groups were noted and may be explained by demographics. For example, those living in rural areas appeared fitter and travelled further to participate in the study. The urban group however were less mobile, and a few were wheelchair users. Inclusion of patients from rural communities addresses one of the limitations in Lavery *et al's* paper³⁰ and our findings suggest that those living in rural communities may be more inclined to engage in exercise and self-management activities, and generally have a more positive outlook on life. However, this could also be explained by people in rural areas needed to travel further to attend the focus groups and therefore had to be fitter to get there. This has implications regarding access to self-management and support groups in rural areas.

Strengths and limitations

A strength of our study was inclusion of HCPs' perspectives thus addressing a current gap in evidence. Involvement of patient representatives on the project steering group provided insightful direction during the design and conduct of the study. Additionally, recruitment of patients across a range of urban and rural areas provided

some, although limited, insight into socioeconomic factors. Key limitations relate to the generalisability of our population, who were based in one English region and most patients were retired. Their views may not be representative of the wider bronchiectasis population.

SUMMARY

This is the first study to explore both patients' and HCPs' views of self-management for bronchiectasis, acknowledging both advantages and barriers. Patients valued peer learning while HCPs acknowledged that 'not one size fits all'. Patient motivation is clearly important and linked to acceptability of interventions. The need for an individual, flexible and responsive self-management intervention was evident and relevant professional knowledge was essential for effective delivery. It is clear that patients' psychosocial and socioeconomic circumstances may influence adoption of self-management interventions and activation of self-management behaviours and that personal characteristics of patients and HCPs could affect uptake and engagement with interventions.

This study has identified key aspects for consideration that will inform future development, delivery and sustainability of self-management programmes for adults with bronchiectasis. Although consensus on the design, structure and delivery of self-management programmes was not evident, other potentially facilitating aspects were apparent. These include the need to direct attention to an individual, tailored approach that reflects both local needs, including accessibility, and availability of resources. Acceptability to patients is important and any self-management intervention should not add to the disease burden, thus optimising motivation. Education of HCPs will be crucial to any self-management programmes and should include training for supporting behaviour change. Future research should aim to elicit additional information on the influence of psychosocial determinants of patients' engagement with self-management interventions including literacy, health beliefs, economic factors, and peer/social support.

Contributors CAK: conceived the idea, sourced funding, developed the protocol, sought ethical and other permissions, acted as principal and chief investigator and was accountable for all aspects of the work related to the accuracy/integrity of any part of the work, analysed the findings and developed the manuscript. AT: developed the protocol, assisted in day-to-day operational running of the study, recruited participants, gained signed informed consent, collected the data, sought ethical and other permissions, analysed the findings and contributed to the manuscript development. DL: developed the protocol, recruited participants, gained signed informed consent, collected the data, analysed the findings and contributed to the manuscript development. SS: conceived the idea, sourced funding, developed the protocol, provided professorial support and advice to the research team and contributed to the manuscript development with final approval of the version published.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval This study was approved by NHS London Harrow Research Ethics Committee (ref 18/L0/1671).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Original data are available upon reasonable request from corresponding author: kellyc@edgehill.ac.uk.

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REFERENCES

- Chang AB, Bell SC, Torzillo PJ, *et al*. Chronic suppurative lung disease and bronchiectasis in children and adults in Australia and New Zealand thoracic Society of Australia and New Zealand guidelines. *Med J Aust* 2015;202:21-3.
- Dudgeon EK, Crichton M, Chalmers JD. "The missing ingredient": the patient perspective of health related quality of life in bronchiectasis: a qualitative study. *BMC Pulm Med* 2018;18:81.
- Goeminne PC, Hernandez F, Diel R, *et al*. The economic burden of bronchiectasis - known and unknown: a systematic review. *BMC Pulm Med* 2019;19:54.
- Chalmers JD, Aliberti S, Blasi F. Management of bronchiectasis in adults. *Eur Respir J* 2015;45:1446-62.
- O'Brien C, Guest PJ, Hill SL, *et al*. Physiological and radiological characterisation of patients diagnosed with chronic obstructive pulmonary disease in primary care. *Thorax* 2000;55:635-42.
- Goeminne PC, De Soya A. Bronchiectasis: how to be an orphan with many parents? *Eur Respir J* 2016;47:10-13.
- Quint JK, Millett ERC, Joshi M, *et al*. Changes in the incidence, prevalence and mortality of bronchiectasis in the UK from 2004 to 2013: a population-based cohort study. *Eur Respir J* 2016;47:186-93.
- Snell N, Gibson J, Jarrold I, *et al*. Epidemiology of bronchiectasis in the UK: Findings from the British lung foundation's 'Respiratory health of the nation' project. *Respir Med* 2019;158:21-3.
- Aliberti S, Sotgiu G, Lapi F, *et al*. Prevalence and incidence of bronchiectasis in Italy. *BMC Pulm Med* 2020;20:15.
- T Hill A, L Sullivan A, D Chalmers J, *et al*. British thoracic Society guideline for bronchiectasis in adults. *Thorax* 2019;74:1-69.
- Polverino E, Goeminne PC, McDonnell MJ, Pieter C, *et al*. European respiratory Society guidelines for the management of adult bronchiectasis. *Eur Respir J* 2017;50:1700629.
- McShane PJ, Naureckas ET, Tino G, *et al*. Non-Cystic fibrosis bronchiectasis. *Am J Respir Crit Care Med* 2013;188:647-56.
- Taylor SJC, Pinnock H. Supported self-management for respiratory conditions in primary care. *Primary Care Respiratory* 2017;4:11-15.
- Lenferink A, Brusse-Keizer M, van der Valk PD, *et al*. Self-Management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *Cochrane Database Syst Rev* 2017;8:CD011682.
- Peytremann-Bridevaux I, Arditi C, Gex G, *et al*. Chronic disease management programmes for adults with asthma. *Cochrane Database Syst Rev* 2015;5:CD007988.
- McCullough AR, Tunney MM, Elborn JS, *et al*. 'All illness is personal to that individual': a qualitative study of patients' perspectives on treatment adherence in bronchiectasis. *Health Expect* 2015;18:2477-88.
- Kelly C, Grundy S, Lynes D, *et al*. Self-Management for bronchiectasis. *Cochrane Database Syst Rev* 2018;2:CD012528.
- Kelly CA, Kirkcaldy AJ, Pilkington M, *et al*. Research priorities for respiratory nursing: a UK-wide Delphi study. *ERJ Open Res* 2018;4:00003-2018-2018.
- Seale C, Silverman D. Ensuring rigour in qualitative research. *Eur J Public Health* 1997;7:379-84.
- Tsang A, Lynes D, McKenzie H. P246 a systematic review of self-management support interventions for adult bronchiectasis patients: a realist synthesis. *Thorax* 2019;74:A223-4.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
- Annoni S, Bellofiore A, Repossini E, *et al*. Effectiveness of chest physiotherapy and pulmonary rehabilitation in patients with non-

- cystic fibrosis bronchiectasis: a narrative review. *Monaldi Arch Chest Dis* 2020;90. doi:10.4081/monaldi.2020.1107. [Epub ahead of print: 12 Feb 2020].
- 23 Patel S, Cole AD, Nolan CM, *et al.* Pulmonary rehabilitation in bronchiectasis: a propensity-matched study. *Eur Respir J* 2019;53:1801264.
 - 24 Alcaraz-Serrano V, Gimeno-Santos E, Scioscia G, *et al.* Association between physical activity and risk of hospitalisation in bronchiectasis. *Eur Respir J* 2020;55:1902138.
 - 25 Basavaraj A, Choate R, Addrizzo-Harris D, *et al.* Airway clearance techniques in bronchiectasis: analysis from the United States bronchiectasis and non-TB mycobacteria research registry. *Chest* 2020;158:1376–84.
 - 26 Gatheral TL, Rushton A, Evans DJ, *et al.* Personalised asthma action plans for adults with asthma. *Cochrane Database Syst Rev* 2017;4:CD011859.
 - 27 Brockwell C, Stockl A, Clark A. Randomised controlled trial of the effect, cost and acceptability of a bronchiectasis self-management intervention. *Chron Respir Dis* 2020.
 - 28 Hester KLM, Ryan V, Newton J, *et al.* Bronchiectasis information and education: a randomised, controlled feasibility trial. *Trials* 2020;21:331.
 - 29 UK Government. Government digital inclusion strategy, 2014. Available: <https://www.gov.uk/government/publications/government-digital-inclusion-strategy/government-digital-inclusion-strategy> [Accessed 23 Nov 2020].
 - 30 Lavery K, O'Neill B, Elborn JS, *et al.* Self-Management in bronchiectasis: the patients' perspective. *Eur Respir J* 2007;29:541–7.
 - 31 Kelly C. Does specialist respiratory education make a difference to practice? *Nurse Educ Pract* 2010;10:308–15.
 - 32 Guo S-E, Shen H-C, Okoli C, *et al.* Generalist versus specialist nurses' knowledge, attitudes, and behavioral intentions toward promoting pulmonary rehabilitation for patients with chronic obstructive pulmonary disease: a cross-sectional correlational study. *Medicine* 2018;97:e12975.
 - 33 Boaventura R, Sibila O, Agusti A, *et al.* Treatable traits in bronchiectasis. *Eur Respir J* 2018;52:1801269.
 - 34 Taylor SJC, Pinnock H, Epiphaniou E. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: prisms – practical systematic review of self-management support for long-term conditions. *NIHR Journals Library* 2014.
 - 35 Hughes S, Lewis S, Willis K, *et al.* The experience of facilitators and participants of long term condition self-management group programmes: a qualitative synthesis. *Patient Educ Couns* 2017;100:2244–54.
 - 36 Hughes S, Lewis S, Willis K, *et al.* Participants' experiences of and perceived value regarding different support types for long-term condition self-management programmes. *Chronic Illn* 2019;174239531986943.
 - 37 Oates GR, Niranjan SJ, Ott C, *et al.* Adherence to pulmonary rehabilitation in COPD: a qualitative exploration of patient perspectives on barriers and facilitators. *J Cardiopulm Rehabil Prev* 2019;39:344–9.
 - 38 Hibbard JH, Stockard J, Mahoney ER, *et al.* Development of the patient activation measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004;39:1005–26.
 - 39 Greene J, Hibbard JH, Alvarez C, *et al.* Supporting patient behavior change: approaches used by primary care clinicians whose patients have an increase in activation levels. *Ann Fam Med* 2016;14:148–54.
 - 40 McCullough AR, Ryan C, O'Neill B, *et al.* Defining the content and delivery of an intervention to change adherence to treatment in Bronchiectasis (CAN-BE): a qualitative approach incorporating the theoretical domains framework, behavioural change techniques and stakeholder expert panels. *BMC Health Serv Res* 2015;15:342.
 - 41 Roberts ME, Lowndes L, Milne DG, *et al.* Socioeconomic deprivation, readmissions, mortality and acute exacerbations of bronchiectasis. *Intern Med J* 2012;42:e129–36.
 - 42 British Lung Foundation (BLF). The battle for breath: the impact of lung disease in the UK, 2016. Available: <https://www.blf.org.uk/policy/the-battle-for-breath-2016> [Accessed 23 Nov 2020].